



END OF LIFE CARE BIBLIOGRAPHY MARCH 2003

1: Adv Gerontol 2002;10:131-5

New challenges and old problems: end of life care and the dilemma of prognostic accuracy.

Tanneberger KS, Pannuti F, Malavasi I, Mariano P, Strocchi E.

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Dignity of the natural end of life for everybody is one of the new great challenges of medicine and social care for the beginning 21st century. However, many end of life care providing doctors are confused about how to categorize the help they give. One of the central problems is predicting the life expectancy of an individual patient. Difficulties in this field can become ethical dilemmas when physicians are obliged to predict accurately a patient's prognosis as the basis for a certain care strategy. Clinical estimation of the duration of life for patients with end of life cancer needs experience and training. Education programmes in the field should include this topic much more until now. Prognosis should be based more on proven indices and less on intuition. However, there is no doubt that daily clinical practice limits the use of highly sophisticated computer-based score models. Even maximal accuracy of prognosis will not exclude the risk of errors in a great part of patients. This limits their classification in care categories too strictly defined. Health care systems should avoid models for care with standards and budgets based on prognostic estimates and the medical community should avoid claim by disciplines of certain categories of patients defined by their prognoses. What we need is a network of assistance for incurable patients with single parts defined by patients needs and not by predicted life expectancy. Separating palliative and terminal care is artificial and often in contrast to the needs of the patients.

PMID: 12577701 [PubMed - in process]

2: Am J Alzheimers Dis Other Dement 2002 Sep-Oct;17(5):299-302

Communicating with dementia patients on hospice.

Thompson PM.

St Coleman Consulting, Rochester, New York, USA.

There are distinct differences in caring for the "typical " hospice patient as opposed to the hospice patient who has Alzheimer's disease. The entire long-term care team, from volunteers to physicians, can benefit from hospice training in this area. This article addresses this topic in terms of what to be aware of in the disease process, understanding and responding to the caregiver's experience and needs, and, of course, patient care. Particular communication techniques are

presented to facilitate interactions with the dementia patient at each of the stages of his or her disease.

PMID: 12392267 [PubMed - indexed for MEDLINE]

3: Am J Cardiol 2003 Mar 1;91(5):583-4

Using implantable devices to improve end-of-life care.

Martin D.

Department of Cardiovascular Medicine, Lahey Clinic Medical Center, Burlington, Massachusetts, USA

PMID: 12615265 [PubMed - in process]

4: Am J Hosp Palliat Care 2003 Jan-Feb;20(1):11-2

Nurses and caring.

Rousseau PC, Kukulka D.

VA Medical Center, Phoenix, Arizona, USA.

PMID: 12568432 [PubMed - indexed for MEDLINE]

5: Am J Hosp Palliat Care 2003 Jan-Feb;20(1):13-22

Attitudes toward care of the terminally ill: an educational intervention.

Frommelt KH.

Clarke College, Dubuque, Iowa, USA.

This quasiexperimental study examined the effect of an educational program on attitudes toward caring for terminally ill persons and their families.

Participants were 115 undergraduate students: intervention group, N = 49; control group, N = 66. Pre- and post-intervention measurements were done with the Frommelt Attitude Toward Care of the Dying Scale (FATCOD, Form B). Students in the intervention group participated in a semester-long (15-week, 45-hour) educational program. Demographic variables, including age, gender, religion, major area of study, influence of religious beliefs, profession, previous education, and past or present experience with loss were evaluated. Statistical analyses (t-test, ANOVA, ANCOVA, and APVs) indicated a significant positive change in the attitude scores of the intervention group and no significant change in the attitude scores of the control group.

Publication Types:

Clinical Trial

Controlled Clinical Trial

PMID: 12568433 [PubMed - indexed for MEDLINE]

6: Am J Hosp Palliat Care 2003 Jan-Feb;20(1):23-33

Spiritual pain: a comparison of findings from survivors and hospice patients.

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The article presents comparative research findings on the notion of "spiritual pain." The findings from interviews with hospice patients affirm the previously published, preliminary conceptualization of spiritual pain from interviews with survivors. However, while the survivor findings highlight the potential for spiritual pain associated with life after high-tech curative treatment, the hospice patient data emphasize the protectiveness of the hospice experience for deflecting the possibility of spiritual pain. It is anticipated the discussion of comparative findings will affirm the importance of researching this "ignored dimension" and, in so doing, will enrich our understanding of the spiritual dimension of healthcare. The work is part of a program presently developing a

language of spirituality through research.
PMID: 12568434 [PubMed - indexed for MEDLINE]

7: Am J Nurs 2003 Mar;103(3):50-8
Cultural Considerations in End-of-Life Care.
Mazanec P, Tyler MK.
How a dying patient's ethnic identity, age, and spiritual beliefs influence care-the sixth in a series on palliative nursing.
PMID: 12626940 [PubMed - in process]

8: Am J Nurs 2001 Dec;101(12):75-8
A sound partnership for end-of-life care.
Alexander C, McKenna S.
Murray State University, Department of Nursing, Murray, KY, USA.
PMID: 12585069 [PubMed - indexed for MEDLINE]

9: Am J Phys Med Rehabil 2003 Feb;82(2):152-7
The ethics of advance directives: a rehabilitation perspective.
Stein J.
Spaulding Rehabilitation Hospital, Boston, Massachusetts 02114, USA.
Advance directives, including living wills and durable healthcare powers of attorney, have achieved broad acceptance by the healthcare system in the United States. Living wills may include provisions for limitation of care in the event of severe disability. These provisions pose ethical concerns in view of societal misconceptions of the quality of life of individuals with disabilities and the inability of people to predict their own capacity to adapt successfully to a disability. Greater reliance on durable healthcare powers of attorney for situations involving disability is proposed, with an emphasis on improving the education of healthcare proxies designated through this mechanism in the quality of life experienced by people with disabilities.
PMID: 12544762 [PubMed - indexed for MEDLINE]

10: Ann Intern Med 2003 Feb 18;138(4):335-7
Hospice benefits and phase I cancer trials.
Byock I, Miles SH.
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Medicare denies hospice coverage to patients with terminal illnesses who enroll as participants in phase I studies, which assess the toxicity and dosing of potential treatments for incurable diseases. Federal regulations require patients to forgo curative therapies, and they interpret phase I agents as treatment for the terminal condition for which hospice care was elected. Thus, by enrolling as a participant in a phase I trial, a patient otherwise eligible for hospice is rendered ineligible. Private insurers have similar provisions for children and adults younger than 65 years of age. Such exclusions are not defensible on ethical or clinical grounds. Policymakers, insurers, and institutional review boards all have a role in resolving this problem.
PMID: 12585832 [PubMed - indexed for MEDLINE]

11: Ann Intern Med 2003 Feb 4;138(3):208-11
Professional organizations' position statements on physician-assisted suicide: a case for studied neutrality.
Quill TE, Cassel CK.

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Position statements opposing legalization of physician-assisted suicide by organizations such as the American College of Physicians-American Society of Internal Medicine rightly emphasize that palliative care should be the standard of care for the dying, and that the inadequacies that exist in its delivery should be remedied. But such position statements generally understate the limitations of palliative care to alleviate some end-of-life suffering, and they do not provide adequate guidance about how physicians should approach patients with intractable suffering who are prepared to die. In this manuscript, we briefly present data about severe suffering before death for terminally ill patients, including those enrolled in hospice programs. We also review some of what is known about requests and responses for physician-assisted suicide in Oregon and in the rest of the United States. Preliminary data from Oregon suggest that legally sanctioned access to physician-assisted suicide is used by a very small number of patients and seems to be associated with improved delivery of hospice and palliative care. Physicians of good will, deep religious convictions, and considerable palliative care experience exist on both sides of the debate about legalization of physician-assisted suicide. In an effort to respect this diversity, and to encourage our profession to continue to struggle with the genuine dilemmas faced by some patients toward the end of their lives and by their families, we argue in favor of medical organizations' taking a position of studied neutrality on this contentious issue.

PMID: 12558360 [PubMed - indexed for MEDLINE]

12: Ann Oncol 2002;13 Suppl 4:247-50

Interventional palliative treatment options for lung cancer.

Noppen N.

Academic Hospital, Interventional Endoscopy Clinic, Respiratory Division, Brussels, Belgium.

Publication Types:

Review

Review, Tutorial

PMID: 12401697 [PubMed - indexed for MEDLINE]

13: Ann Oncol 2002;13 Suppl 4:257-64

Palliative care in hospital, hospice, at home: results from a systematic review.

Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AG, Hood K, Douglas HR, Normand CE.

University of Wales College of Medicine, Velindre NHS Trust, Velindre Hospital, Cardiff, UK.

Publication Types:

Review

Review, Academic

PMID: 12401699 [PubMed - indexed for MEDLINE]

14: Appl Nurs Res 2003 Feb;16(1):65-9

Could lack of clarity in written advance directives contribute to their ineffectiveness? A study of the content of written advance directives.

Nolan MT.

Marie T. Nolan, DNSc, RN, Associate Professor, School of Nursing, The Johns Hopkins University, Beltsville, MD.

Since 1991, advance directives have failed to have a significant impact on end

of life care. One reason is that despite widespread interest in these documents, few individuals have chosen to issue advance directives. Another reason reported in several studies is that the conditions under which the patient intended the directives to apply are unclear as are some of the treatments requested or declined. The purpose of this study was to describe instructions commonly included in written advance directives concerning the conditions under which the directives should apply and the treatments that are requested or declined. Five hundred consecutive closed medical records were reviewed from the medical and surgical departments of an urban hospital. These records produced 40 (8%) advance directive documents. Patient instructions indicating when the directives should take effect and which treatments should be declined or provided were summarized. Nurses and other health professionals can use this information to assist in patients in making their advance directives as clear as possible and to make patients more aware of the potential limitations of these types of written instructions. Copyright 2003, Elsevier Science (USA). All rights reserved.

PMID: 12624865 [PubMed - in process]

15: Arch Intern Med 2003 Mar 10;163(5):609-12

The Value of Disease Severity in Predicting Patient Readiness to Address End-of-Life Issues.

Pfeifer MP, Mitchell CK, Chamberlain L.

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BACKGROUND: Although patient-physician discussion is the most important tool for end-of-life planning, less than 30% of seriously ill patients have held these discussions. While physicians use objective disease severity and recent clinical events to trigger end-of-life discussions, it is not known if such findings predict patient readiness. We evaluated the ability of disease severity measures and recent clinical events to predict patient readiness for end-of-life discussions in patients with chronic lung disease. **METHODS:** The desire for discussion about end-of-life care was evaluated in 100 outpatients with a diagnosis of chronic lung disease presenting for pulmonary function testing. Objective disease severity was indicated by the percentage of the predicted forced expiratory volume, use of oral corticosteroids, a functional status score, frequency of recent hospitalizations, and required use of mechanical ventilation. **RESULTS:** In multivariate analysis, patient desire for an end-of-life discussion with the physician was not associated with percentage of predicted forced expiratory volume in 1 second (odds ratio [OR], 0.99; 95% confidence interval [CI], 0.96-1.03), oral corticosteroid use (OR, 1.34; 95% CI, 0.40-4.54), functional status score (OR, 1.37; 95% CI, 0.34-5.56), hospitalizations in the past year (OR, 0.33; 95% CI, 0.09-1.20), or previous mechanical ventilation (OR, 1.37; 95% CI, 0.34-5.56). **CONCLUSIONS:** Patients appear no more or less interested in end-of-life discussions at later stages of chronic lung disease. Physicians cannot use disease severity measures or recent clinical events to accurately predict when patients desire end-of-life discussions. Focusing on physician skill in using specific communication strategies for patients at all stages of illness may be the most promising approach to increasing end-of-life discussions.

PMID: 12622608 [PubMed - in process]

16: BMJ 2003 Feb 15;326(7385):368

Dying from cancer in developed and developing countries: lessons from two

qualitative interview studies of patients and their carers.

Murray SA, Grant E, Grant A, Kendall M.

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OBJECTIVE: To describe the experiences of illness and needs and use of services in two groups of patients with incurable cancer, one in a developed country and the other in a developing country. DESIGN: Scotland: longitudinal study with qualitative interviews. Kenya: cross sectional study with qualitative interviews. SETTINGS: Lothian region, Scotland, and Meru District, Kenya.

PARTICIPANTS: Scotland: 20 patients with inoperable lung cancer and their carers. Kenya: 24 patients with common advanced cancers and their main informal carers. MAIN OUTCOME MEASURES: Descriptions of experiences, needs, and available services. RESULTS: 67 interviews were conducted in Scotland and 46 in Kenya. The emotional pain of facing death was the prime concern of Scottish patients and their carers, while physical pain and financial worries dominated the lives of Kenyan patients and their carers. In Scotland, free health and social services (including financial assistance) were available, but sometimes underused. In Kenya, analgesia, essential equipment, suitable food, and assistance in care were often inaccessible and unaffordable, resulting in considerable unmet physical needs. Kenyan patients thought that their psychological, social, and spiritual needs were met by their families, local community, and religious groups. Some Scottish patients thought that such non-physical needs went unmet. CONCLUSIONS: In patients living in developed and developing countries there are differences not only in resources available for patients dying from cancer but also in their lived experience of illness. The expression of needs and how they are met in different cultural contexts can inform local assessment of needs and provide insights for initiatives in holistic cancer care.

Publication Types:
Multicenter Study
PMID: 12586671 [PubMed - indexed for MEDLINE]

17: BMJ 2003 Feb 1;326(7383):271-3

Assisted suicide and euthanasia in Switzerland: allowing a role for non-physicians.

Hurst SA, Mauron A.

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Publication Types:

Review

Review, Tutorial

PMID: 12560284 [PubMed - indexed for MEDLINE]

18: Caring 2003 Jan;22(1):48-50

2002 hospice legislative regulatory summary .

Neigh J.

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PMID: 12557466 [PubMed - indexed for MEDLINE]

19: Chest 2003 Jan;123(1):266-71

Comment in:

Chest. 2003 Jan;123(1):16-8.

Impact of a proactive approach to improve end-of-life care in a medical ICU.

Campbell ML, Guzman JA.

Palliative Care Service, Detroit Receiving Hospital, and the Division of Pulmonary and Critical Care Medicine, Wayne State University, Detroit, MI, USA. STUDY OBJECTIVES: To assess the impact of a proactive case finding approach to end-of-life care for critically ill patients experiencing global cerebral ischemia (GCI) after cardiopulmonary resuscitation and multiple organ system failure (MOSF) in comparison to historical control subjects. DESIGN: Comparative study of retrospective and prospective cohorts. SETTING: Medical ICU of a university hospital. INTERVENTIONS: Patterns of end-of life care for patients with MOSF and GCI obtained through a retrospective chart review were compared to proactive case finding facilitated by the inpatient palliative care service. Interventions included identification of patient's advance directives or preferences about end-of life care, if any; assistance with discussion of the prognosis and treatment options with patients or their surrogates; and implementation of palliative care strategies when treatment goals changed to a focus on comfort measures. RESULTS: Although our retrospective data demonstrated a high percentage of do-not-resuscitate decisions for the patients under investigation, a considerable time lag elapsed between identification of the poor prognosis and the establishment of end-of-life treatment goals (4.7 +/- 2.4 days and 3.5 +/- 0.5 days for patients with MOSF and GCI, respectively [mean +/- SE]). The proactive case finding approach decreased hospital length of stay (mean, 20.6 +/- 4.1 days vs 15.1 +/- 2.5 days and 8.6 +/- 1.6 days vs 4.7 +/- 0.6 days for MOSF and GCI patients, respectively; p = 0.063 and < 0.001, respectively). More importantly, a proactive palliative care intervention decreased the time between identification of the poor prognosis and the establishment of comfort care goals (7.3 +/- 2.9 days vs 2.2 +/- 0.8 days and 6.3 +/- 1.2 days vs 3.5 +/- 0.4 days for MOSF and GCI patients, respectively; p < 0.05 for both), decreased the time dying patients with MOSF remained in the ICU, and reduced the use of nonbeneficial resources, thus reducing the cost of care. CONCLUSIONS: Proactive interventions from a palliative care consultant within this subset of patients decreased the use of nonbeneficial resources and avoided protracted dying. PMID: 12527629 [PubMed - indexed for MEDLINE]

20: Chest 2003 Jan;123(1):16-8

Comment on:

Chest. 2003 Jan;123(1):266-71.

End-of-life care and eudaemonia.

Fromm GB.

Publication Types:

Comment

Editorial

PMID: 12527596 [PubMed - indexed for MEDLINE]

21: Chest 2003 Jan;123(1 Suppl):312S-331S

End-of-life care in patients with lung cancer.

Griffin JP, Nelson JE, Koch KA, Niell HB, Ackerman TF, Thompson M, Cole FH Jr; American College of Chest Physicians.

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Evidence-based practice guidelines for end-of-life care for patients with lung cancer have been previously available only from the British health-care system.

Currently in this setting, there has been increasing concern in attaining control of the physical, psychological, social, and spiritual distress of the patient and family. This American College of Chest Physicians'-sponsored multidisciplinary panel has generated recommendations for improving quality of life after examining the English-language literature for answers to some of the most important questions in end-of-life care. Communication between the doctor, patient, and family is central to the active total care of patients with disease that is not responsive to curative treatment. The advance care directive, which has been slowly evolving and is presently limited in application and often circumstantially ineffective, better protects patient autonomy. The problem-solving capability of the hospital ethics committee has been poorly utilized, often due to a lack of understanding of its composition and function. Cost considerations and a sense of futility have confused caregivers as to the potentially important role of the critical care specialist in this scenario. Symptomatic and supportive care provided in a timely and consistent fashion in the hospice environment, which treats the patient and family at home, has been increasingly used, and at this time is the best model for end-of-life care in the United States.

Publication Types:

Guideline

Practice Guideline

Review

Review, Academic

PMID: 12527587 [PubMed - indexed for MEDLINE]

22: Clin Nurse Spec 2003 Jan;17(1):19-21

The role of nebulized opioids in managing terminal dyspnea: implications for the clinical nurse specialist.

Doorley J, Hobbs M, Delaney E, Murphy J.

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Publication Types:

Review

Review, Multicase

PMID: 12544116 [PubMed - indexed for MEDLINE]

23: CMAJ 2003 Feb 4;168(3):265-70

Trends in the place of death of cancer patients, 1992-1997.

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BACKGROUND: Although many patients with cancer would prefer to die at home, most die in hospital. We carried out a study to describe the yearly trends in the place of death between 1992 and 1997 and to determine predictors of out-of-hospital death for adults with cancer in Nova Scotia. **METHODS:** In this population-based study, we linked administrative health data from 2 databases - the Nova Scotia Cancer Centre Oncology Patient Information System and the Queen Elizabeth II Health Sciences Centre Palliative Care Program - for all adults in Nova Scotia who died of cancer from 1992 to 1997. We also used grouped neighbourhood income information from the 1996 Canadian census. Death out of hospital was defined as death in any location other than an acute care hospital facility. We used logistic regression analysis to identify the odds of dying out of hospital over time and to identify factors predictive of out-of-hospital death. **RESULTS:** A total of 14 037 adults died of cancer during the study period.

The data for 101 people were excluded because of missing information regarding place of death. Of the remaining 13 936 people, 10 266 (73.7%) died in hospital and 3670 (26.3%) died out of hospital. Over the study period the proportion of people who died out of hospital rose by 52%, from 19.8% (433/2182) in 1992 to 30.2% (713/2359) in 1997. Predictors associated with out-of-hospital death included year of death (for 1997 v. 1992, adjusted odds ratio [OR] 1.8, 95% confidence interval [CI] 1.5-2.0), female sex (adjusted OR 1.2, 95% CI 1.1-1.3), age (for > or = 85 v. 18-44 years, adjusted OR 2.2, 95% CI 1.7-2.8), length of survival (for 61-120 v. < or =60 days, adjusted OR 2.2, 95% CI 1.8-2.6; for 121-180 v. < or =60 days, adjusted OR 2.5, 95% CI 2.2-2.8), having received palliative radiation (adjusted OR 0.8, 95% CI 0.7-0.9) and region of death (Cape Breton v. Halifax, adjusted OR 0.5, 95% CI 0.5-0.6). Among Halifax residents, registration in the Palliative Care Program was also a significant predictor of out-of-hospital death (adjusted OR 1.4, 95% CI 1.2-1.7). Tumour group, neighbourhood income and residence (urban v. rural) were not predictive of out-of-hospital death in multivariate analysis. INTERPRETATION: Over time, more patients with cancer, especially women, elderly people and people with longer survival after diagnosis, died outside of hospital in Nova Scotia. PMID: 12566330 [PubMed - indexed for MEDLINE]

24: Conn Med 2003 Jan;67(1):49

End-of life care.

Coomaraswamy RP.

Publication Types:

Letter

PMID: 12630187 [PubMed - in process]

25: Crit Care 2003 Feb;7(1):11-2

Beyond ethical dilemmas: improving the quality of end-of-life care in the intensive care unit.

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Consensus guidelines on providing optimal end-of-life care in the intensive care unit (ICU) are important tools. However, despite 30 years of ethical discourse and consensus on many of the principles that guide end-of-life care in the ICU, care remains inadequate. Although consensus on the most challenging ethical aspects of some cases will remain elusive, this need not deter clinicians from engaging in practical quality improvement, best practice, and educational interventions to provide compassionate care to all critically ill patients, including those who ultimately die.

Publication Types:

Editorial

PMID: 12617732 [PubMed - in process]

26: Crit Care Med 2003 Mar;31(3):S167-71

Critical care research on patients with advance directives or do-not-resuscitate status: Ethical challenges for clinician-investigators.

Williams MA, Haywood C Jr.

Clinician-investigators face challenges in conducting research on critically ill patients when they have do-not-resuscitate orders, advance directives, or are in need of end-of-life care. Potential conflicts of interest for

clinician-investigators include either financial stakes or academic and reputational stakes. The dual roles for intensive care unit physician or nurse clinician-investigators as healthcare professionals and scientists also present conflicts of interest, as does the dual purpose for the physical plant of the intensive care unit, which simultaneously serves as a site for patient care and a site for clinical research. Intensive care unit patients who become human research subjects also have dual roles that present conflict or confusion that can result in the therapeutic misconception. There are no scientifically or ethically sound reasons to exclude patients from participation in critical care research based on the presence of an advance directive or do-not-resuscitate order, as it would create a biased study sample that does not reflect the critically ill patient population, and it would treat a large group of potential research subjects differently from others without justification. There are four values in tension for critical care clinician-investigators in relation to patients/human research subjects: curative intent, palliative intent, research, and fiduciary obligations. A patient's decision to participate in research does not relieve clinician-investigators of their obligation to serve patient/human research subject's interests, even when doing so involves decisions to limit or withdraw life-sustaining interventions or withdraw the patient/human research subject from research. Critical care research involving patients with advance directives or do-not-resuscitate status is both possible and desirable because it is just, respects patient autonomy, and results in study populations that better reflect the clinical population in all respects.
PMID: 12626963 [PubMed - in process]

27: Crit Care Med 2003 Jan;31(1):60-4

Life-sustaining treatments in patients who died of chronic congestive heart failure compared with metastatic cancer.

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Department of Medicine, Albert Einstein Medical Center, Jefferson Health System, Philadelphia, PA, USA.

INTRODUCTION: Life-sustaining treatments such as cardiopulmonary resuscitation, mechanical ventilation, vasopressors, and admission to critical care units, if used when recovery chance was remote, may unnecessarily cause discomfort and increase cost of care. Outcomes of these treatments in chronic, refractory congestive heart failure (CHF) and metastatic cancer patients were poor. Although both conditions were the leading causes of death, previous studies indicated that hospice utilization and do-not-resuscitate orders were less common in CHF patients. To date, the use of life-sustaining treatments in these patients and the influence of do-not-resuscitate orders remains unknown. **METHOD:** We conducted a retrospective medical record review of the patients who died in our hospital in 1999 and had discharge diagnoses of CHF or cancer. Medical records were screened for seriously ill patients according to the modified SUPPORT criteria, which included patients with CHF functional class IV or ejection fraction of 20% or less at baseline and with metastatic cancer not receiving any curative treatments. Analyses were performed using SPSS, version 9.0. **RESULTS:** There were 58 and 82 patients in CHF and cancer groups, respectively. CHF patients were older (78.8 vs. 67.3 yrs, $p < .001$) and stayed in the hospital longer (11.9 vs. 7.9 days, $p = .014$). The majority of patients in both groups received do-not-resuscitate orders before death (84% and 72%, respectively). CHF patients received do-not-resuscitate orders later than did cancer patients (6.7 vs. 2.8 days, $p = .006$). However, there was no significant difference in prevalence of do-not-resuscitate orders. All studied

life-sustaining treatments were more common in CHF patients than in cancer patients. A subgroup analysis between CHF patients with do-not-resuscitate orders and those without do-not-resuscitate orders revealed cardiopulmonary resuscitation to be the only treatment less common in those with do-not-resuscitate orders. CONCLUSIONS: Patients who died of chronic, refractory CHF received more life-sustaining treatments than did patients who died of metastatic cancer.

PMID: 12544994 [PubMed - indexed for MEDLINE]

28: Curr Pain Headache Rep 2003 Apr;7(2):89-97

The Psychiatric Management of End-of-life Pain and Associated Psychiatric Comorbidity.

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Involvement by psychiatrists in the care of patients who are terminally ill has been limited historically; however, psychiatrists increasingly are participating in the care of these people who are facing the most challenging times of their lives. Pain management is considered to be an area of subspecialization for psychiatrists beyond their traditional role of being psychopharmacologists and psychotherapists. Biologically focused psychiatrists are able to address neuropsychiatric disorders, including pain and depression in the medically ill, and actively improve the quality of life for dying patients and their family members. This article provides a review of the recent literature that has addressed the involvement of psychiatrists in end-of-life care. Beginning with an example of the scientific aspects of cancer-related treatment from a patient's perspective, and into the major treatment considerations, this article addresses pain, its recognition, and management challenges when the end of life approaches. The prompt recognition of frequently overlooked and underestimated concomitant depressions, delirium, dementia, and other mental disorders is important for mental health specialists. The importance of psychiatric care for patients who are terminally ill and the role of psychiatrists in the phase of care also are discussed.

PMID: 12628050 [PubMed - in process]

29: Gastroenterol Nurs 2003 Jan-Feb;26(1):26-30

Palliative care update for gastroenterology nurses.

Raudonis BM.

Changing demographics, specifically an aging population associated with an increase of chronic and terminal illness, have highlighted the need for palliative or comfort care in nursing from the time of diagnosis through the dying process. Palliative or comfort care is now on the national healthcare agenda. The purpose of this article is to provide an update on selected palliative care and end-of-life issues and resources related to practice, education, research, and policy for gastroenterology nurses. In addition, selecting one of the suggested resources to review on a regular basis will provide the reader with a strategy for keeping up-to-date in palliative and end-of-life care.

PMID: 12582294 [PubMed - in process]

30: Gastroenterol Nurs 2002 Nov-Dec;25(6):267-8

End-of-life nursing care.

Ferraro CB.

Publication Types:

Letter

PMID: 12488691 [PubMed - indexed for MEDLINE]

31: Geriatr Nurs 2002 Nov-Dec;23(6):296-301

Long-term care nurses' knowledge of end-of-life care.

Raudonis BM, Kyba FC, Kinsey TA.

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Long-term care (LTC) facilities usually contract with hospice agencies to provide palliative (comfort) care to their terminally ill residents, yet only 1% of nursing home residents enroll in hospice care. Integrating hospice services with nursing home services presents many challenges. One of the most critical challenges is the lack of education in palliative care among physicians, licensed nurses, and certified nursing assistants in LTC settings. A study of 164 licensed nurses from 24 LTC facilities in north central Texas found deficiencies in their knowledge of palliative care. The mean score on the Palliative Care Quiz for Nursing was 12.3 of a possible 20 (62%, SD = 2.7). Implications for practice include a critical need for in-service education on end-of-life content for practicing LTC nurses and integration of such content in all curricula for future nurses.

PMID: 12494000 [PubMed - indexed for MEDLINE]

32: Geriatr Nurs 2002 Nov-Dec;23(6):302-10

The nurse's role in end-of-life decision-making for patients and families.

Briggs L, Colvin E.

Gundersen Lutheran Medical Foundation, La Crosse, Wis, USA.

This article discusses some of the cultural changes required for organizations to build systems that move beyond mere completion of the advance directive to advance care planning that affects end-of-life decision-making. It specifically describes one organization's educational approach to clarifying the role of the nurse as patient advocate within these cultural changes and suggests strategies to help the nurse gain necessary competence in end-of-life decision-making.

PMID: 12494001 [PubMed - indexed for MEDLINE]

33: Geriatr Nurs 2002 Nov-Dec;23(6):312-5

Implementing a do-not-resuscitate order in an adult day center.

Combs PL, Stahl LD.

Parma Community General Hospital Community Health and Wellness Center, USA.

Participants in adult day centers may indicate that they do not want to be resuscitated if they have a life-threatening health crisis. To comply with their wishes the adult day center needs to have policies procedures in place to professionally legally safeguard the institution. These authors describe the process for developing implementing the do-not-resuscitate policy.

PMID: 12494003 [PubMed - indexed for MEDLINE]

34: Hastings Cent Rep 2002 Jul-Aug;32(4):14-21

Vitalism revitalized.... Vulnerable populations, prejudice, and physician-assisted death.

Mayo DJ, Gunderson M.

One of the most potent arguments against physician-assisted death hinges on the worry that people with disabilities will be subtly coerced to accept death

prematurely. The argument is flawed. There is nothing new in PAD: the risk of coercion is already present in current policies about end of life care. And to hold that any such risk is too much is tacitly to endorse vitalism and to deny that people with disabilities are capable of choosing authentically.
PMID: 12362519 [PubMed - indexed for MEDLINE]

35: Health Soc Work 2002 Nov;27(4):313-4; author reply 314-5
Comment on:

Health Soc Work. 2001 Aug;26(3):160-6.
Ethical issues in the social worker's role in physician-assisted suicide.
Miller P, Hedlund S.
Publication Types:

Comment
Letter

PMID: 12494725 [PubMed - indexed for MEDLINE]

36: Hematol Oncol Clin North Am 2002 Jun;16(3):701-14
Delirium in patients with advanced cancer.

Lawlor PG, Bruera ED.

Department of Oncology, Division of Palliative Care Medicine, University of Alberta, Tertiary-level Palliative Care Unit, Grey Nuns Community Hospital, Edmonton, Alberta, Canada T6L 5X8. plawlor@sfh.ie

Managing delirium is of major importance in end-of-life care and frequently gives rise to controversies and to clinical and ethical dilemmas. These problems arise from a number of causes, including the sometimes-poor recognition or misdiagnosis of delirium despite its frequent occurrence. Delirium generates major symptomatic of distress for the patient, consequent stress for the patient's family, the potential to misinterpret delirium symptomatology, and behavioral management challenges for health care professionals. Paradoxically, delirium is potentially reversible in some episodes, but in many patients delirium presents a nonreversible terminal episode. Greater educational efforts are required to improve the recognition of delirium and lead to a better understanding of its impact in end-of-life care. Future research might focus on phenomenology, the development of low-burden instruments for assessment, communication strategies, and the family education regarding the manifestations of delirium. Further research is needed among patients with advanced cancer to establish a predictive model for reversibility that recognizes both baseline vulnerability factors and superimposed precipitating factors. Evidence-based guidelines should be developed to assist physicians in more appropriate use of sedation in the symptomatic management of delirium.

Publication Types:

Review
Review, Tutorial

PMID: 12170576 [PubMed - indexed for MEDLINE]

37: Home Healthc Nurse 2003 Jan;21(1):32-7

A pain assessment tool for people with advanced Alzheimer's and other progressive dementias.

Lane P, Kuntupis M, MacDonald S, McCarthy P, Panke JA, Warden V, Volicer L.
Geriatric Research Education Clinical Center, Unit 62 ABN, Edith Nourse Rogers Memorial Veterans Hospital, 200 Springs Road, Bedford, MA 01730, USA.
Patricia.lane2@med.va.gov

Appropriate pain management can only be achieved through accurate pain assessment that is individualized, ongoing, and well documented. Assessment tools must focus on the patient as the authority on pain's existence and severity; however, self-reports are not feasible when patients lose their ability to verbally communicate. This article describes a scientifically proven pain assessment tool that can be used for patients with advanced dementia and Alzheimer's Disease.

PMID: 12544460 [PubMed - indexed for MEDLINE]

38: Int J Palliat Nurs 2002 Dec;8(12):566-73

Comment in:

Int J Palliat Nurs. 2003 Jan;9(1):39.

An integrated care pathway for the last two days of life: Wales-wide benchmarking in palliative care.

Fowell A, Finlay I, Johnstone R, Minto L.

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Functional benchmarking assesses performance and practice across a broad range of settings and carries the potential to effect change in practice. An integrated care pathway (ICP) can assist in the benchmarking process, defining desired outcomes for specific patient groups over a designated time frame. Any variations to the agreed course of care are documented using the 'variance sheet'. This article describes the Wales-wide implementation of an ICP for the last two days of life. The project has enabled an ongoing centralized collection and analysis of variance sheets, which reflect the care of the dying patient in four different care settings crossing the voluntary and statutory sectors.

Initial analysis of the first 500 variance sheets to be generated by the ICP for the last two days of life indicates that the management of pain, agitation, excess respiratory secretions and mouth care may be problematic. The same problems were experienced across acute, hospice, specialist inpatient units and community care. Closing the audit cycle involves incorporating the information from the variance analysis into clinical practice.

PMID: 12560798 [PubMed - indexed for MEDLINE]

39: Int J Palliat Nurs 2002 Dec;8(12):598-9

Comment on:

Int J Palliat Nurs. 2002 Oct;8(10):481-8.

A commentary on 'Joe's story: reflections on a difficult interaction between a nurse and a patient's wife'.

Seber P.

Faculty of Healthcare Counsellors and Psychotherapists of the British Association of Counselling and Psychotherapy.

Publication Types:

Comment

PMID: 12560803 [PubMed - indexed for MEDLINE]

40: Int J Palliat Nurs 2002 Dec;8(12):591-3

Use of quality-of-life scores in care planning in a hospice setting: the theme of revelation.

Hill N.

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This article follows an earlier one in which measurement of quality of life (QOL) was used in developing patient-care plans and to identify differences in QOL assessment between nurses and patients as an aid to reflective practice. The present article discusses how the theme of revelation emerged from the insights of those in the study. The process of measuring, and subsequent use of, QOL scores increased understanding between nurse and patients. Some nurses were surprised at how different their perception of a patient's QOL was from that of the patient. Completing QOL questionnaires also gave some patients new insights. How such revelations might be used to improve QOL are discussed.

PMID: 12560801 [PubMed - indexed for MEDLINE]

41: J Affect Disord 2002 May;69(1-3):53-60

Depression and grief reactions in hospice caregivers: from pre-death to 1 year afterwards.

Chentsova-Dutton Y, Shacter S, Hutchin S, Strause L, Burns K, Dunn L, Miller M, Zisook S.

Department of Psychiatry, University of California at San Diego and VA Healthcare Systems, 0603-R, 9500 Gilman Drive, La Jolla, CA 92093-0603, USA.

BACKGROUND: As the US population ages, more and more individuals will find themselves facing the demanding task of caring for terminally ill family members. Yet strikingly little is known about the emotional toll such caregiving exacts from caregivers, or how the stresses and strains of caregiving affect later grief reactions. This study examines the emotional adjustment and grief intensity of bereaved caregivers from their prebereavement (caregiving) baseline through the first year after the death and compares the effects of caregiving and subsequent bereavement on spouses and adult children. **METHODS:** Forty-eight adult children and spousal caregivers of hospice patients and 36 controls were evaluated shortly before the deaths of their loved ones and again at 2, 7, and 13 months after their deaths. All subjects were administered the Hamilton Rating Scale for Depression, Brief Symptom Inventory, and the Texas Revised Instrument of Grief. **RESULTS:** Depression and other indices of psychological distress are highest during the caregiving period and during the first few months after the death, before decreasing over the duration of the first year. Many symptoms of grief remain prominent as long as 13 months after the death of a parent or a spouse. There were no differences in intensity of grief, depression or other indices of distress between bereaved children and bereaved spouses.

CONCLUSIONS:

The magnitude of the stress of caregiving may be underestimated. Depression is at least as likely to emerge in the context of caregiving as it is in the postbereavement period. Therapeutic interventions may need to take into consideration the expected distress associated with caregiving and the chronicity of grief reactions. **LIMITATIONS:** The large dropout rate, reliance on self-report ratings and demographically homogeneous sample may limit generalizability of findings.

PMID: 12103452 [PubMed - indexed for MEDLINE]

42: J Am Board Fam Pract 2003 Jan-Feb;16(1):58-62

End-of-life care for a man with developmental disabilities.

Lohiya GS, Tan-Figueroa L, Crinella FM.

Fairview Developmental Center, Costa Mesa, Calif 92626, USA.

BACKGROUND: Science can artificially maintain many essential life functions.

Does such care prolong life or dying? METHODS: A case is described of a patient with developmental disability with unknown health care choices who was hospitalized for drug-resistant urosepsis. He developed aspiration pneumonia, deep vein thrombosis, and respiratory arrest. He required gastrostomy, tracheostomy, artificial ventilation, parenteral nutrition, hemodialysis, multiple anti-infective agents, and blood transfusions. On day 58, a bioethics committee recommended against cardiopulmonary resuscitation. On day 66, the patient's conservator concurred but required continuation of artificial ventilation. To the dismay of some caretakers, the patient continued to receive intrusive care until his death on day 104. The hospital charge was \$709,206.

RESULTS AND CONCLUSION: Hospital care of patients with mental incapacity can be clinically and ethically challenging. End-of-life decisions can be facilitated when the patient's legal representative and physician actively advocate the patient's best interests and communicate frequently and openly. Suggestions are made for such exigencies.

PMID: 12583651 [PubMed - in process]

43: J Am Coll Surg 2003 Jan;196(1):106-12

Guidelines for withholding or termination of resuscitation in prehospital traumatic cardiopulmonary arrest: joint position statement of the National Association of EMS Physicians and the American College of Surgeons Committee on Trauma.

Hopson LR, Hirsh E, Delgado J, Domeier RM, McSwain NE, Krohmer J; National Association of EMS Physicians.; American College of Surgeons Committee on Trauma.

Department of Emergency Medicine, University of Michigan Health System, Ann Arbor, MI, USA.

Publication Types:

Duplicate Publication

Guideline

Practice Guideline

Review

Review Literature

PMID: 12517561 [PubMed - indexed for MEDLINE]

44: J Am Coll Surg 2003 Jan;196(1):141-51

Clinical research for surgeons in palliative care: challenges and opportunities.

Easson AM, Lee KF, Brasel K, Krouse RS.

Division of Surgical Oncology, Princess Margaret Hospital, University Health Network, Toronto, Ontario, Canada.

PMID: 12517566 [PubMed - indexed for MEDLINE]

45: J Am Med Womens Assoc 2003 Winter;58(1):44-8

Antecedents of euthanasia and suicide among older women.

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lroscoe@hsc.usf.edu

OBJECTIVES: To identify the characteristics of older women who sought Jack Kevorkian's assistance in dying and to compare them with those of an age-matched sample who committed suicide. METHOD: This retrospective case-control study

compared all 18 women age 55 and older who died with the assistance of Jack Kevorkian and whose deaths were investigated in Oakland County, Michigan from 1995 to 1997 with all 15 women age 55 and older who committed suicide in the same county during the same time period. We coded 203 variables in 7 domains from medical examiner files, including autopsy findings. RESULTS: Significantly more of Kevorkian's cases had amyotrophic lateral sclerosis or multiple sclerosis ($p = .018$), a recent decline in health ($p = .031$), or inadequately controlled pain ($p = .041$). Women who committed suicide had more prevalent chronic illnesses and were more likely to have been diagnosed with clinically significant depression or other psychiatric disorders ($p = .023$). Both groups were significantly less likely to be married ($p < .001$) and more likely to be divorced ($p < .001$) than US Census data would predict. CONCLUSIONS: The different vulnerabilities of older women who want to die and either commit suicide or seek assistance deserve continued careful research. Poorly controlled pain was a factor in seeking assistance in dying, and depression and psychiatric disorders characterized older women who committed suicide in our study. Not having a spouse may increase isolation and reinforce the hopelessness of women who are living with catastrophic illness.

PMID: 12553642 [PubMed - indexed for MEDLINE]

46: J Clin Anesth 2002 Sep;14(6):401-4

Comment on:

J Clin Anesth. 2002 Sep;14(6):467-73.

Perioperative do not resuscitate orders: caring for the dying in the operating room and intensive care unit.

Caruso LJ, Gabrielli A, Layon AJ.

Publication Types:

Comment

Editorial

PMID: 12393105 [PubMed - indexed for MEDLINE]

47: J Clin Anesth 2002 Sep;14(6):467-73

Comment in:

J Clin Anesth. 2002 Sep;14(6):401-4.

Guidelines for perioperative do-not-resuscitate policies.

Waisel DB, Burns JP, Johnson JA, Hardart GE, Truog RD.

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This paper reviews some of the difficulties in implementing perioperative reevaluation of do-not-resuscitate (DNR) orders and suggests several strategies for perioperative DNR policies. Policies should be written, designed and implemented at the level of the institution, and be sufficiently flexible to permit the tailoring of the perioperative DNR order to the individual patient. Policies should unambiguously state that reevaluation is required, delineate responsibilities for reevaluating the DNR order, state all the available options, define the necessary documentation, and list resources for help.

PMID: 12393121 [PubMed - indexed for MEDLINE]

48: J Clin Ethics 2002 Fall;13(3):188-202

A mediation/medical advisory panel model for resolving disputes about end-of-life care.

Buchanan SF, Desrochers JM, Henry DB, Thomassen G, Barrett PH Jr.

Clinical Research Unit of Kaiser Permanente of Colorado, Denver, USA.
PMID: 12624887 [PubMed - in process]

49: J Clin Oncol 2003 Feb 15;21(4):728-35

Barriers to hospice care among older patients dying with lung and colorectal cancer.

McCarthy EP, Burns RB, Davis RB, Phillips RS.

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PURPOSE: To identify factors associated with hospice enrollment and length of stay in hospice among patients dying with lung or colorectal cancer. **METHODS:** We used the Linked Medicare-Tumor Registry Database to conduct a retrospective analysis of the last year of life among Medicare beneficiaries diagnosed with lung or colorectal cancer at age ≥ 66 years between January 1, 1973, and December 31, 1996, in the Surveillance, Epidemiology, and End Results Program who died between January 1, 1988, and December 31, 1998. Our outcomes of interest were time from cancer diagnosis to hospice enrollment and length of stay in hospice care. We used Cox proportional hazards regression to adjust for demographic and clinical information. **RESULTS:** We studied elderly patients dying with lung cancer ($n = 62,117$) or colorectal cancer ($n = 57,260$). Overall, 27% of patients ($n = 16,750$) with lung cancer and 20% of patients ($n = 11,332$) with colorectal cancer received hospice care before death. Median length of stay for hospice patients with lung and colorectal cancer was 25 and 28 days, respectively. Overall, 20% of patients entered hospice within 1 week of death, whereas 6% entered more than 6 months before death. Factors associated with later hospice enrollment include being male; being of nonwhite, nonblack race; having fee-for-service insurance; and residing in a rural community. Many of these factors also were associated with shorter stays in hospice. **CONCLUSION:** Although use of hospice care has increased dramatically over time, specific patient groups, including men, patients residing in rural communities, and patients with fee-for-service insurance continue to experience delays in hospice enrollment.

PMID: 12586813 [PubMed - indexed for MEDLINE]

50: J Clin Oncol 2003 Feb 1;21(3):549-54

Approaching the end of life: attitudes, preferences, and behaviors of African-American and white patients and their family caregivers.

Phipps E, True G, Harris D, Chong U, Tester W, Chavin SI, Braitman LE.

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PURPOSE: To investigate differences in attitudes, preferences, and behaviors regarding end of life in terminally ill patients and their designated family caregivers. **PATIENTS AND METHODS:** 68 African-American and white patients with stage III-B or IV lung or stage IV colon cancer and 68 patient-designated family caregivers interviewed between December 1999 and May 2001. **RESULTS:** White patients were more likely to have a durable power of attorney (34% v 8%, $P = .01$) and were more likely to have a living will (LW; 41% v 11%, $P = .004$) than were African-American patients. More African-American than white patients desired the use of life-sustaining measures (cardiopulmonary resuscitation [CPR], mechanical ventilation, tube feeding) in their current condition (all $P > .12$). In a near-death condition, African-American patients were more likely than white patients to desire each of the life-sustaining measures (all $P < .004$). There was

no patient-caregiver agreement beyond chance regarding preferences for initiation of CPR, tube feeding, or mechanical ventilation in the patient's current condition or in the near-death condition. In the near-death condition in patients without LWs, there was disagreement in 46% of patient-caregiver pairs about CPR, in 50% about mechanical ventilation, and in 43% about tube feeding. CONCLUSION: Although most patients and families endorse the primacy of the patient in decisions at end of life, the majority do not take supporting actions. Disagreements between patients and families about the use of life-sustaining measures in patients without LWs may result in patients' preferences being superseded at end of life.
PMID: 12560448 [PubMed - indexed for MEDLINE]

51: J Gerontol Nurs 2002 Dec;28(12):31-9; quiz 48-9
Dehydration in terminally ill patients. Perceptions of long-term care nurses. Critchlow J, Bauer-Wu SM.
Phyllis F. Cantor Center, Dana-Farber Cancer Institute, 44 Binney Street, Boston, MA 02115, USA.
Dehydration in terminally ill patients has been found to be beneficial and to improve the quality of an individual's last few days of life. As the population continues to age, more individuals are cared for in long-term care (LTC) facilities, where they tend to spend their final days. Previous studies have examined the perceptions and attitudes of hospice nurses, acute care nurses, physicians, and caregivers; however, no such studies have evaluated LTC nurses. It is necessary to know LTC nurses' perceptions and attitudes so they can be offered the education needed to provide the best quality care for terminally ill patients. The purpose of this study was to describe how nurses working with elderly individuals in LTC perceived terminal dehydration (TD). Long-term care nurses (N = 64) were surveyed using a modified version of an established 10-item instrument. Significant findings included a positive correlation between age and positive perception of TD--as nurse age increased, a more positive view of TD was expressed. Also, the number of deaths witnessed was positively associated with the belief that TD was beneficial. In general, responses to the individual survey items were quite varied, representing inconsistencies in attitudes and care of dying LTC patients. The results of this descriptive study indicate the debate concerning the benefits of TD continues and remains an important topic for the LTC nurse.
PMID: 12567824 [PubMed - indexed for MEDLINE]

52: J Law Med 2002 Nov;10(2):221-31
Euthanasia: why it doesn't matter (much) what the doctor thinks and why there is no suggestion that doctors should have a duty to kill.
Bagaric M, Amarasekara K.
School of Law, Deakin University, Burwood, Vic. 3125, Australia.
A major reason that The Netherlands has taken a different approach to the rest of the world on such a fundamental moral issue is that the courts and legislature in that country have accorded the interests of doctors a cardinal role in the euthanasia debate. This article argues that the interests of doctors are of only incidental and peripheral relevance in relation to the moral status of euthanasia. The moral status of euthanasia has little to do with the preparedness of doctors to administer the lethal injection or their general attitude towards the practice. Euthanasia is principally about the interests of the patient and the impact that the practice may have on the community in general, not preserving the conscience or improving the working life of doctors.

PMID: 12497736 [PubMed - indexed for MEDLINE]

53: J Law Med Ethics 2002 Fall;30(3):459-60

Assisted suicide: court strikes down Ashcroft directive.

Wiley LF.

Publication Types:

Legal Cases

PMID: 12497708 [PubMed - indexed for MEDLINE]

54: J Nurs Res 2002 Dec;10(4):237-45

The essence of spirituality of terminally ill patients.

Chao CS, Chen CH, Yen M.

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The purpose of this hermeneutic study was to investigate the essence of spirituality of terminally ill patients. In-depth unstructured interviews were used as the method for data collection. In the six-month period of data collection, the researcher was in the role of a hospice palliative care consultant who directly took care of the subject patients in a hospice ward of a teaching hospital. The six subjects were selected purposively according to various demographic backgrounds. Interview transcripts provided the data for analysis. The results were composed of four constitutive patterns and ten themes. The first constitutive pattern was "Communion with Self" which included three themes: (1) Self-identity--spirituality is the discovery of the authentic self. (2) Wholeness--a human being is full of contradictions but still in wholeness. (3) Inner peace--spirituality is negotiating conflicts for self-reconciliation. The second constitutive pattern was "Communion with others" which included two themes: (1) Love--spirituality is a caring relationship but not an over-attachment to others. (2) Reconciliation--spirituality is to forgive and to be forgiven. The third constitutive pattern was "Communion with Nature" which included two themes: (1) Inspiration from the nature--spirituality is the resonance of the marvelous beauty of nature. (2) Creativity--spirituality is conceiving imaginatively. The fourth constitutive pattern was "Communion with Higher Being" which included three themes: (1) Faithfulness--spirituality is keeping the trust dependably. (2) Hope--spirituality is claiming possibilities. (3) Gratitude--spirituality is giving thanks and embracing grace. The scientific rigor of this qualitative research as well as the strength and limitations of the study are reported. Implications for hospice palliative care and future research are recommended.

PMID: 12522736 [PubMed - indexed for MEDLINE]

55: J Pain Symptom Manage 2003 Mar;25(3):236-46

Dying patients' need for emotional support and personalized care from physicians. Perspectives of patients with terminal illness, families, and health care providers.

Wenrich MD, Curtis JR, Ambrozy DA, Carline JD, Shannon SE, Ramsey PG.

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This study addressed the emotional and personal needs of dying patients and the ways physicians help or hinder these needs. Twenty focus groups were held with 137 individuals, including patients with chronic and terminal illnesses, family members, health care workers, and physicians. Content analyses were performed based on grounded theory. Emotional support and personalization were 2 of the 12

domains identified as important in end-of-life care. Components of emotional support were compassion, responsiveness to emotional needs, maintaining hope and a positive attitude, and providing comfort through touch. Components of personalization were treating the whole person and not just the disease, making the patient feel unique and special, and considering the patient's social situation. Although the levels of emotional support and personalization varied, there was a minimal level, defined by compassion and treating the whole person and not just the disease, that physicians should strive to meet in caring for all dying patients. Participants also identified intermediate and advanced levels of physician behavior that provide emotional and personal support.
PMID: 12614958 [PubMed - in process]

56: J Pain Symptom Manage 2003 Feb;25(2):128-32

Surveys to Assess Satisfaction with End-of-Life Care. Does Timing Matter?

Casarett DJ, Crowley R, Hirschman KB.

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The goals of this study were to determine whether post-death surveys of family members cause more distress if they are administered closer in time to the patient's death, and whether family members are less likely to respond to earlier surveys. Caregivers of hospice patients were randomly assigned to receive a survey at 2 weeks (n = 107) or at 6 weeks (n = 100) after the patient's death. Response rates and self-reported distress experienced in completing the survey were recorded. There were no differences in self-ratings of distress between 2- and 6-week surveys, and response rates were identical (2-week: 54%; 6-week: 54%). Distress and response rate do not appear to be influenced by the timing of data collection, even when surveys are administered very soon after death.

PMID: 12590028 [PubMed - in process]

57: J Pain Symptom Manage 2003 Jan;25(1):19-28

Physicians' interactions with health care teams and systems in the care of dying patients: perspectives of dying patients, family members, and health care professionals.

Carline JD, Curtis JR, Wenrich MD, Shannon SE, Ambrozy DM, Ramsey PG. Department of Medical Education and Biomedical Informatics, University of Washington, Seattle, WA 98195, USA.

This study investigated the specific physician skills required to interact with health care systems in order to provide high quality care at the end of life. We used focus groups of patients with terminal diseases, family members, nurses and social workers from hospice or acute care settings, and physicians. We performed content analysis based on grounded theory. Groups were interviewed. Two domains were found related to physician interactions with health care systems: 1) access and continuity, and 2) team communication and coordination. Components of these domains most frequently mentioned included taking as much time as needed with the patient, accessibility, and respect shown in working with health team members. This study highlights the need for both physicians and health care systems to improve accessibility for patients and families and increase coordination of efforts between health care team members when working with dying patients and their families.

PMID: 12565185 [PubMed - indexed for MEDLINE]

58: J Palliat Med 2002 Oct;5(5):756-7

The Web-based worksheet: an opportunity for prompt, consistent, and expert feedback in a community-based hospice experience.

Ogle K, Thompson ME, Noel MM.

Palliative Care Education and Research Program, Michigan State University, East Lansing, Michigan 48824, USA.

We faced a challenge in providing a consistent high-quality learning experience in hospice care, especially because our community-based medical school has students rotating in hospices in six separated communities and the number of faculty with expertise in palliative care is limited. To address these concerns, a Web-based worksheet with interaction with a central campus faculty member was designed for use in a hospice module in a family practice clerkship.

PMID: 12572980 [PubMed - indexed for MEDLINE]

59: J Palliat Med 2002 Oct;5(5):759-62

What role should the nephrologist play in the provision of palliative care?

Siegler EL, Del Monte ML, Rosati RJ, von Gunten CF.

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PMID: 12572982 [PubMed - indexed for MEDLINE]

60: J Palliat Med 2002 Oct;5(5):687-95

Comment in:

J Palliat Med. 2002 Oct;5(5):659-60.

Estimation of confusion prevalence in hospice patients.

Nowels DE, Bublitz C, Kassner CT, Kutner JS.

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BACKGROUND: Confusion is common among ill patients and has broad consequences for their care and well-being. The prevalence of confusion in hospice patients is unknown. **OBJECTIVES:** Describe the prevalence, severity, and manifestations of nurse-identified confusion and estimate the prevalence of delirium in hospice patients. **DESIGN:** Cross-sectional descriptive study. **SETTING:** Nineteen hospices in the Population-based Palliative Care Research Network (PoPCRN). **PATIENTS:** Adult patients receiving care from participating hospices, February 15 to April 1, 2000. **MEASUREMENT/ANALYSIS:** Hospice nurses estimated prevalence, severity, behavioral manifestations, and consequences of confusion during the preceding week. Confused and nonconfused patients were compared using standard bivariate and stratification techniques. Logistic regression identified manifestations associated with problematic confusion. **RESULTS:** Median age of the 299 patients was 78 years; 59% were female, 52% lived at home, and cancer was the most common diagnosis (54%). Fifty percent were confused during the preceding week, 36% of those were severely confused or disabled by confusion. Compared with nonconfused patients, confused patients were less likely to have cancer (64% vs. 43%, $p < \text{or} = 0.001$) and more likely to live in nursing home/assisted living (21% vs. 33%, $p < \text{or} = 0.01$). Disorientation to time or place, impaired short-term memory, drowsiness, and easy distractibility were common manifestations of confusion. When present, confusion caused a problem for the patient, someone else, or both 79% of the time. Inappropriate mood, cancer diagnosis, agitation, and age were the variables predicting problematic confusion. Only 14% of confused patients met criteria for delirium. **CONCLUSIONS:** Confusion among hospice patients was common, frequently severe, and usually problematic.

PMID: 12572967 [PubMed - indexed for MEDLINE]

61: J Palliat Med 2002 Oct;5(5):713-20

Hospice experience and perceptions in nursing homes.

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The purpose of this study was to describe the experiences and perceptions of hospice nurses caring for residents in long-term care facilities. The study used a fax-back survey to gather data from 69 hospice nursing and nurse managers in 24 hospices across one Midwestern state. Respondents reported negative experiences with pain management and care coordination in the nursing home setting. Although hospice is thought to be a benefit to residents, hospice staff report frustration in caring for nursing home patients, especially in trying to control pain. The study identifies opportunities for improvement in hospice and nursing home staff relationships.

PMID: 12572970 [PubMed - indexed for MEDLINE]

62: J Palliat Med 2002 Oct;5(5):721-7

Experience with hospice: reflections from third-year medical students.

Maxwell TL, Passow ES, Plumb J, Sifir RD.

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Nationally, there is a growing emphasis on experiential education and an interest in palliative care for health professionals. Hospice visits were added to the family medicine community rotation for third-year medical students to provide them with first-hand exposure to the hospice experience. Seven significant themes emerged from the students' reflection papers: (1) the value of hospice and the supportive role of the hospice team, (2) the value of empathy, (3) the distinction between acceptance and resignation, (4) the changing face of hope, (5) an understanding of death as a natural event, (6) the quality of family caregiving, and (7) the role of the physician in caring for the dying. The implications for medical education discussed include the value of home visits as a setting for experiences in palliative care and the effectiveness of narrative assignments for encouraging student reflection.

PMID: 12572971 [PubMed - indexed for MEDLINE]

63: J Palliat Med 2002 Oct;5(5):657-8

Aggressive treatment in the terminally ill: right or wrong?

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PMID: 12572961 [PubMed - indexed for MEDLINE]

64: J Palliat Med 2002 Oct;5(5):659-60

Comment on:

J Palliat Med. 2002 Oct;5(5):687-95.

The confusion about confusion.

Chang VT.

Publication Types:

Comment

Editorial

PMID: 12572962 [PubMed - indexed for MEDLINE]

65: J Pastoral Care Counsel 2002 Winter;56(4):409-11

She died with a tear in her eyes.

Jones AJ.

Mundelein United Methodist Church, 25653 N. Willow Spring Rd., Mundelein, IL 60060, USA.

PMID: 12564400 [PubMed - indexed for MEDLINE]

66: JAMA 2003 Feb 26;289(8):981; author reply 981

Comment on:

JAMA. 2002 Dec 4;288(21):2732-40.

Shared decision making about withdrawing treatment.

Workman S.

Publication Types:

Comment

Letter

PMID: 12597737 [PubMed - indexed for MEDLINE]

67: Jpn J Clin Oncol 2002 Dec;32(12):506-11

Clinical factors associated with suicidality in cancer patients.

Akechi T, Nakano T, Akizuki N, Nakanishi T, Yoshikawa E, Okamura H, Uchitomi Y. Psycho-Oncology Division, National Cancer Center Research Institute East, Kashiwa, Chiba, Japan.

BACKGROUND: Previous epidemiological studies have indicated that the risk of suicide in cancer patients is higher than that of the general population. In addition, euthanasia and physician-assisted suicide (PAS) have recently become controversial medical, ethical and legal issues all over the world. Although suicide in cancer patients and appropriate management of cancer patients with suicidality are critical issues in clinical oncology practice, there have been very few studies to understand suicidality in cancer patients. The purpose of this study was to explore the clinical factors associated with suicidality in Japanese patients with cancer. METHODS: We investigated the clinical factors associated with suicidality in cancer patients by analyzing the consultation data of patients referred to the Psychiatry Division, National Cancer Centre Hospital and Hospital East, Japan. RESULTS: Of 1713 psychiatric referrals, 62 (3.6%) were related to suicidality, including 44 cases with suicidal ideation, 10 suicide attempts and eight cases who had requested euthanasia and/or continuous sedation. Most of the patients suffered from physical distress and/or psychiatric disorders. The results of a multivariate analysis comparing cancer patients with a psychiatric referral related to suicidality and those referred for other reasons indicated that impaired physical functioning and major depression were significant associated factors. CONCLUSIONS: Our findings suggest that early detection and appropriate management of major depression and comprehensive care improving physical functioning may help to prevent suicide and manage suicidality in Japanese cancer patients.

PMID: 12578898 [PubMed - indexed for MEDLINE]

68: Lancet Oncol 2003 Feb;4(2):73-4

Improving palliative care for cancer.

Higginson IJ, Finlay IG.

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PMID: 12573348 [PubMed - indexed for MEDLINE]

69: Mo Med 2002 Nov-Dec;99(10):571-6

Spirituality and end-of-life care.

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As dying patients adjust to the irreversible nature of their illness, their needs and focus of care changes. Spiritual issues may become a central concern for them, and addressing these issues can be key to relieving suffering.

Physicians, unfortunately, have little training in this area and are often uncomfortable discussing spirituality. In this article, we address the role of spirituality in end-of-life care, and discuss a format for spiritual assessment. We hope this will encourage more comprehensive patient-centered, end-of-life care.

PMID: 12534145 [PubMed - indexed for MEDLINE]

70: Mo Med 2002 Nov-Dec;99(10):566-70

Questions & answers about hospice: a guide for Missouri's physicians.

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Hospice provides multidisciplinary care to dying patients with and without cancer. Most adults would prefer to be cared for in their home or that of a family member. This guide provides answers to the questions most commonly asked of physicians. Its goal is to facilitate a better understanding of what hospice does, who is eligible, physician roles, and how physicians can use hospice to help their patients.

PMID: 12534144 [PubMed - indexed for MEDLINE]

71: Mo Med 2002 Nov-Dec;99(10):556-9

Pain relief at the end-of-life: a clinical guide.

Anderson CM.

Ellis Fischel Cancer Center, University of Missouri, Columbia, USA.

Pain at the end-of-life is usually treatable, but most dying patients are under-treated and die in unnecessary pain. This brief overview will serve to describe the problem of pain at the end-of-life, define the relevant ethical, medical, scientific, and societal issues, and present an optimal pain management plan for this vulnerable and important population. The most important factor is for physicians to make pain control a matter of paramount importance in the care of dying patients.

PMID: 12534142 [PubMed - indexed for MEDLINE]

72: Nurs Forum 2002 Oct-Dec;37(4):24-31

Critique of transcultural practices in end-of-life clinical nursing practice.

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TOPIC: Transcultural nursing practices for terminally ill patients. PURPOSE: To examine several criticisms of transcultural nursing theory in end-of-life care.

SOURCES: Published literature and interviews with nurses. CONCLUSIONS: Nurses often encounter barriers that impede their ability to provide ideal end-of-life

care.

Publication Types:

Review

Review, Tutorial

PMID: 12592835 [PubMed - indexed for MEDLINE]

73: Palliat Med 2003 Jan;17(1):11-20

Quality of life in palliative care: principles and practice.

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In healthcare, most researchers and clinicians agree that quality of life (QOL) is related to symptoms, functioning, psychological and social wellbeing, and probably to a lesser extent to meaning and fulfillment. This multidimensional health-oriented concept has been named health-related quality of life (HRQOL). However, during end-of-life care spirituality and existential issues become more prominent, as well as family members' perception of quality of care. Outcome measures in palliative care require constructs that reflect the specific goals of palliative care, such as improving QOL before death, symptom control, family support and satisfaction, as well as patients' perceptions of 'purpose' and 'meaning of life'. It is generally recommended that internationally developed and validated patient-rated multidimensional questionnaires should be used when assessing HRQOL in research. However, 'multidimensionality', with often more than 10 possible outcomes, is a threat both to statistical analysis and clinical interpretation of data. Preferentially, a more limited number of outcomes based upon the research question(s) should be defined prior to data collection in the study protocol. The researcher needs to carefully evaluate the content of the questionnaire, in addition to other properties, such as the validity and reliability, before the final decision is made with regards to which instrument to use in a given study.

PMID: 12597461 [PubMed - in process]

74: Qual Lett Healthc Lead 2003 Jan;15(1):10-1

New report card compares end-of-life care initiatives across the country.

A report card from Last Acts and the Robert Wood Johnson Foundation takes a first look on a state-by-state basis at how end-of-life care and related issues are approached by healthcare organizations across the country.

PMID: 12610861 [PubMed - in process]

75: S Afr Med J 2002 Dec;92(12):936-7

GP's vision kick-starts palliative training.

Bateman C.

Publication Types:

News

PMID: 12561402 [PubMed - indexed for MEDLINE]